

SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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ASCC Celebrates 25th Anniversary at Conference

The Arkansas Spinal Cord Commission celebrated its 25th anniversary at the conference on June 2, 2000, held at the C.A. Vines 4-H Center in Ferndale. ASCC hosted over 220 clients, family members, professionals, speakers, staff and friends of the Commission in one of the largest conferences to date.

Entitled "New Challenges for a New Century: Celebrating 25 Years and Beyond," the conference offered a variety of opportunities to learn about spinal cord disability related issues and the agency's past and future. Program highlights of the conference included wheelchair athlete **David Kiley** talking about not using your disability as an excuse and **Timothy Elliott**'s

discussion of dealing with stress and depression in everyday life. In addition, Dr. **Edgar Garcia-Rill** presented the latest strategies in spinal cord injury research. Luncheon activities included a his-



tory of the beginnings of the Commission presented by past Executive Director **George Richardson**

and a tribute to all past and present Commission members, staff and friends. **Mrs. Jane Smith** received special recognition for her persistent effort in establishing the Commission as an Arkansas state agency in 1975.

There were ample opportunities to meet with the exhibitors at the conference who offered a wealth of information regarding services ranging from personal care products, new wheelchairs and accessible vans.

A number of nice door prizes were awarded this year. **Mike Morrissey** won a large Igloo ice chest donated *Continued on page 7 - see "Conference 2000"*

ADA Turns 10 Years Old

In July 2000 the Americans with Disabilities Act (ADA) will turn ten years old. When the ADA was passed in 1990, it was anticipated that it would remedy employment discrimination and lack of public accommodations for persons with disabilities in this country. Two of the most notable changes in policy inspired by the ADA have occurred in the past year.

In February 2000, President Clinton signed the Workforce Incentive Improvement Act (WIIA) to help persons with disabilities return to the workforce. To ease the financial and health strain created by returning to work, the WIIA allows persons who receive Medicare to retain their benefits up to eight and one-half years after be-

coming employed. It also sets aside \$150 million in grants to states to allow workers with disabilities to buy into Medicaid.

Another important piece of legislation passed recently is the decision set forth in Olmstead v. L.C. And E.W. Essentially, the Supreme Court ruling in Olmstead reinforced Title II of the ADA. Title II prohibits state and local governments from discriminating in employment, architectural access, public transit and service delivery. The *Olmstead* decision bolsters Title II because it is designed to allow persons with disabilities to have the opportunity to access and use home and community based Continued on page 7 - see "ADA Turns 10 Years Old"

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SPINAL COURIER

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With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at 501-296-1788/800-459-1517/TDD 501-296-1794, or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

Donations this quarter from:

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SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

From the Director

Some things you just remember—birthdays, anniversaries, where you were when Elvis died. For some reason, I remember exactly when I first heard of the ADA (the Americans with Disabilities Act). It was a Sunday afternoon in June of 1989. We were having a meeting to organize the Arkansas Spinal Cord Injury Association and Richard Petty, Advocate Extraordinaire, brought up the ADA. I had no idea what he was taking about. All sorts of acronyms ran through my mind. Finally, I had to show my ignorance and asked, "What is the ADA?"

Richard described a piece of civil rights legislation that sounded like heaven to most of us there: a federal law that would prevent discrimination against people with disabilities and improve accessibility. Over the next year, I learned a lot about the ADA. For the first time in my life, I actually advocated for legislation, writing to my own Congressman and Senators, as well as to those on committees that would hear the bill. One day we all sent telegrams to a particular committee. Senator Dale Bumpers chaired a committee the bill was having trouble passing—we talked to him a lot. By chance, I had the opportunity to visit the White House that spring and heard the President talk about it—and on we pushed.

There was a groundswell of grassroots support in the spring of 1990. People with disabilities climbed the steps of the Capitol and held candle-light vigils. Finally, we watched, as it passed the Senate and squeaked through the House. On July 26, 1990, when President George Bush signed the ADA into law, we celebrated. I will always appreciate him for that.

Little did we know, the work had **just begun**. We had a law; it was a little watered down from what we hoped, but it was federal law. We began our advocacy and education all over again, to make sure people knew about and adhered to it. Who would have guessed the challenges we would meet!

My own small role has included becoming an ADA trainer, doing 50 or 60 presentations over the past ten years, and answering probably a few hundred ADA questions. My favorite training was one we did in 1997 for the Arkansas Architects Association. It was great learning experience for an architect in a wheelchair to try to get in and out of a bathroom door at Hot Springs Rehab Center!

Have there been changes? Definitely! Thanks to folks like Cliff Coates and Verlon McKay and John Haskins—but they had to go to court to get some of them!

The ADA is ten years old this month. Let's celebrate the accomplishments of the past decade, then dig in—we have a lot more work to do!

Cheryl Vines

In memory of Mark Wright
Trilby Maul
Mr. & Mrs. Eldon Lucas
Mr. & Mrs. George McLellan

Mr. & Mrs. Richard Mobley Mr. & Mrs. Jack Sweden In honor of Mrs. Jane Smith Van Spence

Welcome Back, Harry!

On May 4, 2000, a "Welcome Back!" celebration took place in the community of Sherwood featuring Harry Zintel and Popeyes Chicken. The event was hosted by St. Vincent Rehabilitation Hospital. Harry was surrounded by friends, family, therapists, specialists, his doctor, coworkers and well wishers. Channel 11 covered the event, as did the local newspaper.

The staff from St. Vincent's commented, "Harry has been such an inspiration to all of us. We wanted to take part in recognizing how his hard work has paid off, not only for him, but for anyone who has been associated with him." The Team Managers of Popeyes voiced similar sentiments, "We at Popeyes knew Harry would be back. We have kept his position open and are just as excited as Harry to finally have this day happen. He is such a dynamic person to be around."

Harry's "time out" from work was due to a personal injury accident that occurred on December 20.

1999. Harry and his brother were in a motor vehicle that rolled over. Harry was ejected from the vehicle and sustained a spinal cord injury at the T₉ level. His brother suffered cuts and bruises.

Two days after Christmas, Harry left the acute care hospital and entered St. Vincent Rehabilitation Hospital in Sherwood. He was discharged home near the end of January 2000. The Arkansas Spinal Cord Commission assisted with home accessibility and modifications.

If you are in Sherwood, stop at Popeyes on Kiehl Avenue near JFK for some great food and one of the biggest smiles you will ever see. Harry is making a difference and it shows!



Harry Zintel, center, flanked by Danny and Linda Gillilland, Team Managers of Popeyes in Sherwood

Range of Motion

Bone junctions—joints—provide motion within your body and support or bear weight. Each joint is surrounded by muscles, tendons, ligaments and a joint capsule. These provide stability to the joint.

A joint's range of motion (ROM), or number of degrees of motion, is determined by the tightness of the ligaments, tendons, muscles and joint capsule surrounding that joint. Looser or more flexible structures result in more movement, tighter structures in less.

Generally, a person's everyday movements are enough to keep his or her joints flexible. The weakness caused by SCI may interfere with the full ROM. Because of this weakness and the resulting loss of movement, you must find some other means to stretch your joints and maintain flexibility.

Decreased arm, leg and truck ROM tends to increase pressure at localized points rather than allowing its even distribution. This localization significantly increases risk of skin breakdown. Maintaining joint flexibility also tends to decrease muscle spasticity.

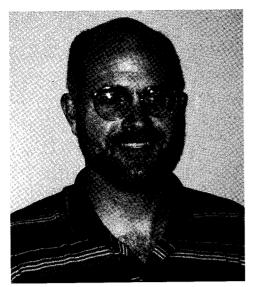
When performing ROM exercises, allow time for your muscles and other structures to loosen and stretch. Move slowly and smoothly. Bouncing your body tends to encourage spastic muscles to tighten.

ROM exercises may include the following:

- Trunk rotation/bending
- Hip abduction/extension
- Hip stretches
- Leg rotation
- Straight leg raise
- Shoulder rotation/extension
- Elbow flexion/extension
- Wrist, thumb and finger flexion/extension

Source: Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury. © 1989, Paralyzed Veterans Of America.

This article was reprinted with permission from PN/Paraplegia News, February, 1999, page 12. Copies of this article are available from PN/Paraplegia News, 2111 E. Highland Avenue, Suite 180, Phoenix, AZ 85016-4702.



ummer and heat go together, at least in Arkansas. This is a dangerous time for anyone with a spinal cord injury (SCI) since impairment of the body's temperature regulation is a problem in persons with a SCI. What makes it worse is that you may not be aware of the problem until it is too late. This makes it essential that you take precautionary and preventive measures to avoid becoming overheated and having a heat stroke.

Body temperature is maintained by a balance between heat production and heat loss. Sensation of hot and cold is located in sensors in the skin and the brain. An individual with SCI does not sense the heat and cannot get rid of heat like an able-bodied individual. The skin is unable to feel the sensation of heat.

The most important mechanisms of heat loss are dilation of peripheral blood vessels (i.e., in your arms and legs), sweating and behavioral changes (e.g., moving to a cooler environment, changing your body position, changing the amount of clothing). In a person with SCI the body's circulatory system is not able to dilate (or expand) the blood vessels of the skin. Sweating below the level of the SCI is severely impaired.

A person with a complete SCI and tetraplegia has the most impaired

Summer Heat and Spinal Cord Injury

by Tom Kiser, M.D., ASCC Medical Director

temperature control and, thus, the highest risk of overheating. Therefore, if you were out in the summer sun you would be unable to sense the heat until your body temperature had risen significantly. By the time you started feeling hot it might be too late to cool off, or your first signs might be symptoms of heat stroke.

Symptoms of heat stroke range from headache, faster breathing, dizziness, and confusion to loss of consciousness. Complications range from breakdown of the muscle tissue, electrolyte disturbances, acute kidney failure to possibly death.

If you, or somebody you know, experience this problem, seek medical attention promptly. Heat stroke is a medical emergency. Until help arrives, attempt to cool the person off as much as possible. Place the person in an air-conditioned place and remove excessive clothing. Use a spray bottle of water or a wet washcloth to cool the skin and massage the skin above the level of the SCI to encourage dilation of blood vessels.

To keep from having problems with heat this summer, please follow these simple suggestions:

- 1. Stay in an air-conditioned place if the temperature is above 90°F. Have an accessible airconditioned automobile or trailer nearby if you have to be outside and away from your home.
- 2. Avoid alcoholic beverages since alcohol suppresses the central brain temperature sensor. It can aggravate the

problem by decreasing your awareness of the heat.

- 3. Wear light and removable clothing and stay in a shady area if possible.
- 4. Drink plenty of water and have a water spray bottle available if you have to be out in the heat.
- 5. Be aware of how able-bodied individuals are responding to the heat. If they are sweating, you are likely to develop heat stroke unless you move to a cooler place.

Enjoy the summer and stay cool!

Old Fashioned Niloak Day

Benton, AR will be holding "2000 Old Fashioned Niloak Day" on **Saturday**, **October 7**. This will be a citywide festival with a craft fair held at the **Saline County Fairgrounds** from **8:00 am to 5:00 pm**.

The festival will offer arts and crafts, great food, hot air balloon rides, a petting zoo, a variety of musical entertainment, horseshoes and the Arkansas Reenactors Association. All proceeds will help support the Senior Center program in Saline County. Admission is \$2 for adults and children under age 12 get in free. Parking at the Fairgrounds is \$2.

So, mark your calendar for Saturday, October 7! Call Old Niloak Day Coordinator Chris Brazil at 501-860-6621 if you have any questions.

Safe Pools Can Prevent SCI

by Linda L. Lindsey, MEd and Barbara Key, MA, UAB Dept. of Physical Medicine & Rehabilitation Center

Did you know that more than 850 spinal cord injuries (SCI) result from diving accidents each year? Of those, nearly 300 occur at home, either in above- or below-ground pools.

Did you know that the consequences of SCI are devastating and costly?

- The majority of diving spinal cord injuries result in the paralysis of all four limbs (quadriplegia/tetraplegia).
- The lifetime medical costs for one spinal cord injury exceed \$1 million (in 1997 dollars).
- SCI diving accidents typically occur in young men between the ages of 15-25 years.
- Lifetime lost wages and benefits for a 25-year-old with tetraplegia typically exceed \$1.5 million.

Many spinal cord injuries that occur in pools can be prevented! Be a responsible pool owner. Make sure your pool is safe!

Survey your pool area using this checklist:

- 1_____Are there depth indicators clearly visible around the pool?
- 2._____Îs the pool and surrounding area well lighted during use?
- 3. _____Do you serve or allow alcohol to be consumed by pool guests?
- 4.____Do you enforce set hours for pool use?
- 5. Is your pool secured with fencing to keep people out during inappropriate hours?
- 6.____Does your pool have a designated diving area?
- 7._____Do you have a lifeguard, or someone trained in water safety, present when guests are at your pool, especially during parties?

Check your answers with those below. Do you agree? Follow these recommendations to make your pool area safe.

- 1. Yes Clearly mark the depth of your pool. You can purchase stick-on depth indicators from your pool supply store.

 Fact: Depth indicators were not present in 75% of the accidents that resulted in SCI.*
- 2. Yes Install and use adequate lighting! Set a timer for automated lighting.

 Fact: 84% of SCIs occurred in pools with inadequate or no lighting.*
- 3. No Do not serve or allow alcohol use by pool guests.

 Fact: 49% of SCIs occurred when consuming alcohol while swimming or diving.*
- 4. <u>Yes</u> Set hours for use. Do not permit unsupervised swimming.

 Fact: 44% of SCIs occurred

during a person's first visit to the pool.*

- 5. Yes Install secure fencing to control usage.

 Fact: 93% of SCIs occur to pool guests—not the owners!*
- 6. Yes Educate guests about pool depth and safe diving area. Mark diving well clearly. Fact: 95% of SCIs occur when diving into less than eight feet of water.*
- 7. Yes Do not swim alone. Have a trained water-safety person present at parties. Instruct guests in proper diving techniques.

 Fact: Almost 50% of SCI occured during a party. No lifeguard is on duty in 94% of accidents that resulted in SCI.*

*Facts taken from: A study by Dr. Michael J. DeVivo of UAB Dept. of PM&R for the National Swimming Pool Foundation. DeVivo, MJ and Sekar, P. Prevention of spinal cord injuries that occur in swimming pools. Spinal Cord 1997; 35:509-515.

Experience the Water — Try Scuba Diving!



Would you like to participate in an exhilarating sport? You should take up scuba diving. The Arkansas Disabled Scuba Association (ADSA), founded in October 1999 by **Bill Hutto**, is headquartered in Benton, AR at Scuba Dreams Dive Training and Travel Center.

They operate as an independent diver training and certifying agency that offers courses developed according to National Association of Underwater Instructors and Handicapped Scuba Association International Physical Performance Standards. This enables the ADSA to train people with a wide range of disabilities, including paraplegia, quadriplegia, blindness, high func-

tioning brain injuries or mild retardation. "Scuba diving is an exciting sport for anyone, but for those who are disabled, it is so much more. It gives them complete freedom from their disability," stated Hutto.

"Dive Buddy" is another program promoted by ADSA that offers able-bodied divers the opportunity to expand the underwater world to include sharing it with a disabled partner.

Try something new and different. Learn scuba diving and involve a friend or family member in the Arkansas Disabled Scuba Association's enjoyable new programs!

AR Rollin' Razorbacks — National Wheelchair Basketball Champions!

Congratulations to the Arkansas Rollin' Razorbacks! They won their fifth National Wheelchair Basketball Championship on April 7-8 in Chicago, IL.

In the semifinal game, the Razor-backs played the Austin Wreckers and won a close contest, 66-60. They advanced to the champion-ship game where they met and

defeated the Denver Nuggets, 59-43.

"The championship game showed wheelchair basketball at its finest," said Razorback Steve Tew. "With a high shooting percentage and



dominating defense, we showed who the number one team in the nation is."

After the championship game, Grant Strohbach was named to the Second All-Tournament Team. Tim Kazee, Jared Johnson, James Coughlin and Darren Schenebeck made the First All-Tournament Team.

Hiring and Managing Attendants

"Managing attendants is like running a small business," said Kirk Hennig, who has used personal care aids since his C₆-C₇ injury 14 years ago. At first he used attendants provided by an agency but he became frustrated with the inconsistent quality of care, due in part to high attendant turnover. After 2-3 years with agency attendants, he decided to hire them himself.

"The first step in the hiring process is to determine the duties you want an attendant to perform," Hennig said. In addition to personal care tasks, these might include house cleaning, laundry, shopping or cooking. A detailed task list and schedule helps determine the hours and days when attendants are needed, and can serve later as a training tool and daily or weekly checklist.

Hennig advertises in the local newspaper but also recommends placing notices on job boards at universities, community colleges and health-related vocational schools. He lists his area of residence and phone number in his ads, but not his street address or last name.

"Careful telephone screening is essential," Hennig said. "You can

learn a lot about someone over the phone," including personality, command of English and whether he or she has the right to work in the U.S.

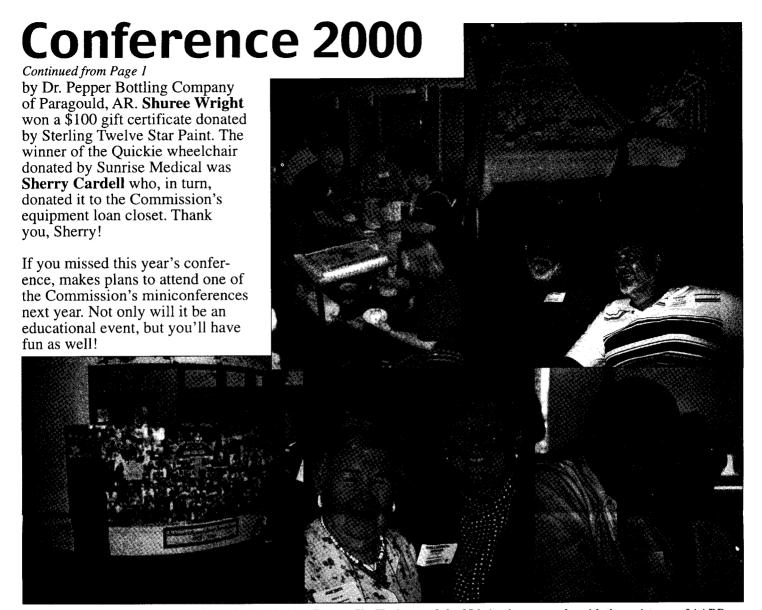
When Hennig is ready to interview someone in person, he mails out an application form and asks the prospect to complete it and bring it to the interview. "People who are late to the interview, don't fill out the application completely, or don't bring references as I ask them to do have not turned out to be good employees in the long term,' Hennig said. After the interview, always call references. For a fee, the State Patrol will do a criminal background check on a candidate. When deciding whether to hire someone, "go with your intuition. If you have a bad feeling, don't say, 'well, I really need someone now, so maybe I'll try this one anyway.' It's not worth it." He estimates that it costs him \$200-\$300 to hire each attendant.

While compatibility is important, Hennig said he avoids hiring friends or family members. It's difficult to have a business relationship during one part of the day and a friend or family relationship at other times. Walt Robinson, who also has tetraplegia, said his wife was doing all his care at first but, "it was a strain on our relationship." Eventually they started using private agencies.

In addition to hiring and training attendants, agencies also provide a replacement if a regular attendant is sick or doesn't show up. Those who hire their own attendants must come up with their own back-up systems. Said Hennig, "It's wise to have a family member know your care routine for emergency purposes."

Most of his former attendants have left Hennig's employment on good terms. But sometimes an attendant must be fired, in which case it's best to "recognize that terminating someone is tough and do it." He suggests having a friend or relative present if you feel threatened by the situation, and getting your keys and other property back right away.

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ASCC Director Cheryl Vines and Commission Member Deanna VanHook served the 25th Anniversary cake with the assistance of AARP volunteers (above left), Mike Wagner, Little Rock, AR, checked his program after visiting the vendor booths (top right), Gary Turner of Pineville, AR, and Van Spence of Wynne, AR, enjoyed the sessions (middle left), former Commission Member Glennis Sharp and his wife, Judy, from Cotter, AR, attended the luncheon celebration (bottom left), Mrs. Jane Smith and Commission Member Sheila Galbraith Bronfman were recognized at the luncheon (bottom middle), and ASCC Bettie Tapp took a look at the collage celebrating persons involved in ASCC's first 25 years of service (bottom left).

ADA Turns 10 Years Old

Continued from Page 1

supports and services to remain living outside of institutions, such as nursing homes and residential care facilities. It acts to ensure access to a wide range of services that will allow persons with disabilities to live in noninstitutional settings more appropriate to their needs.

While all of the developments in disability policy have not been as positive as these, the past decade has brought many opportunities to persons with disabilities because of the ADA. Now, in the ADA's tenth year, we should renew our efforts to continue working in the "Spirit of the ADA."

The Arkansas ADA Roundtable, the Disability Rights Center and the Arkansas Independent Living Council invite you to join them from 10:00 am to 12:00 noon on July 26, 2000, at the Arkansas State Capitol to celebrate the tenth anniversary of the Americans with Disabilities Act. The program will

include an awards ceremony for the winners of the "Spirit of the ADA" essay and art contests. There will also be a special presentation by Lieutenant Governor Winthrop Rockefeller and many other entertaining activities.

If you would like more information about the tenth anniversary celebration for the ADA, please contact **Kristie Soto** in the ASCC Little Rock office at 501-296-1792 / 800-459-1517 (voice) or 501-296-1794 (TDD).

New Videos in the Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at 501-296-1792 or 800-459-1517. Some of the new additions include:

• Uppertone (video) is a commercial video demonstrating equipment which can be used by persons with quadriplegia for unassisted muscle strengthening and conditioning.

- EasyPivot Patient Lift (video) is a commercial video describing the use of this patient lift, which has a different design than a hoyer lift, with persons requiring assistance for transfers.
- Straight Talk to the Newly Diagnosed (video) is a video from the National Multiple Sclerosis Society. Six individuals discuss how they faced the issues of families, exercise, careers, relationships and lifestyles after being diagnosed with MS.

Home Mod Hints from Whirlpool Corporation

The Whirlpool Corporation's appliance information service offers useful hints on modifications for kitchens and laundry rooms. These free publications provide information ranging from inexpensive, quick-fix accessibility helpers to special features on appliances which make independent living easier for disabled customers. The titles of the specific publications are: The Less Challenging Home, The Time Smart Kitchen, Tools for Independent Living, and Designs for Independent Living.

To request copies of these publications, contact the Appliance Information Service at: Whirlpool Corporation, P.O. Box 405, St. Joseph, MI 49085; or call 800-253-1301 / 800-334-6889 (TDD).

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